

Members:

Rep. Vanessa Summers, Chair
Rep. Markt Lytle
Rep. Robert Alderman
Rep. Cleo Duncan
Sen. Richard Worman
Sen. Kent Adams
Sen. Allie Craycraft
Sen. Joseph O'Day



Lay Members:

Hugh Beebe
Capt. Michael Carmin
Nan Daley
Donna Ott
Herbert Grulke
Becky Zaseck

LSA Staff:

Susan Preble, Fiscal Analyst for the Commission
Ann Naughton, Attorney for the Commission

Authority: IC 12-11-7

COMMISSION ON AUTISM

Legislative Services Agency
200 West Washington Street, Suite 301
Indianapolis, Indiana 46204-2789
Tel: (317) 232-9588 Fax: (317) 232-2554

MEETING MINUTES

Meeting Date: August 5, 1998
Meeting Time: 10:30 A.M.
Meeting Place: State House, 200 W. Washington St.,
Room 233
Meeting City: Indianapolis, Indiana
Meeting Number: 3

Members Present: Rep. Vanessa Summers, Chairperson; Rep. Markt Lytle; Rep. Robert Alderman; Sen. Richard Worman; Sen. Allie Craycraft; Sen. Joseph O'Day; Hugh Beebe; Nan Daley; Donna Ott.

Members Absent: Rep. Cleo Duncan; Sen. Kent Adams; Herbert Grulke; Becky Zaseck; Capt. Michael Carmin.

CALL TO ORDER AND OPENING REMARKS

Rep. Summers called the meeting to order at 10:45 a.m. She explained that the meeting would focus exclusively on the testimony of parents of individuals with autism and other interested parties concerning their experiences with the Autism Waiver and the provision of services to their children.

PRESENTATION BY THE AUTISM SOCIETY OF INDIANA

Beth Garlits, President of the Autism Society of Indiana, presented a certificate of appreciation to Sen. Worman for his many years of work on the Commission. She thanked him for his commitment to the implementation of the Medicaid Autism Waiver, and for his personal interest in families. Sen. Worman thanked parents and supporters and encouraged them to continue their grassroots activism.

PUBLIC TESTIMONY REGARDING THE AUTISM WAIVER

Susie Rimstidt, parent of a son with autism, former teacher and Outreach Coordinator for Monroe County Center for Independent Living, stated that although there are problems with the waiver and the waiting list, the waiver remains the most humane way to keep individuals as close to their family homes as possible. She stressed the importance of getting rid of the

waiting list and provided an example of a single-parent family that desperately needs the services the waiver can provide but because of the waiting list, they will have to wait 3 years before they can be helped. Ms. Rimstidt distributed copies of her written testimony to the Commission members.¹

Penny Githens, parent of a son with autism and member of the South Central Indiana Chapter of the Autism Society of America, distributed a handout and testified about the role insurance plays in the ability of individuals with autism to get the services they need.² She argued that if legislation were enacted to require insurance companies to cover more services for individuals with autism it would lower the demand for waivers and may lessen the financial burden on the state. Ms. Githens stated that her insurance policy through Indiana University will cover services for developmental delays, but not autism. After an individual is diagnosed with autism, most insurance companies will no longer provide the same services they continue to provide for those with a diagnosis of developmental delay.

Sen. Worman explained that the General Assembly can't help because it cannot regulate insurance companies due to the passage of ERISA (Employee Retirement Income Security Act) by Congress in 1974. He advised Ms. Githens to lobby her congressmen and suggested that coverage can be negotiable through an employee association or collective bargaining unit.

Sen. Craycraft wondered whether the passage of a resolution would be helpful. Rep. Summers suggested that a letter of concern to the insurance company from the Commission may be in order. Rep. Lytle commented that if an individual with autism cannot get coverage, then the insurance company is discriminating against the handicapped.

A motion to send a letter of concern to Indiana University with a copy to the Department of Insurance was made and passed by unanimous voice vote.

In response to questions from the Commission members, Ann Naughton, staff attorney, shared her understanding of the breadth and limits of recent Kentucky legislation concerning this topic with the Commission. Ms. Naughton then clarified the difference between the traditional state insurance plan (which is self insured) and HMOs (which are regulated by the Department of Insurance) and suggested that Keith Beesley from the Personnel Department would be helpful and able to discuss state benefits.

Karen Demarest, parent of a son with autism, distributed a handout and testified that her 14-year old son has been on the waiver since 1992 and that it has been very helpful.³ Ms. Demarest suggested several areas of improvement, including increasing the number of waiver spots available, making the process of getting on the waiver less difficult, and educating the public about the existence of the waiver. She also testified that once an individual gets on the waiver, it can take up to one year to get a Medicaid number, which is required before services can be received.

Ms. Githens advocated for a voucher system that would allow parents to pay providers directly for services, and commented that parents already hire and fire providers anyway. Rep. Alderman expressed interest in exploring the possibility of a voucher system in Indiana. Ms. Githens explained that she believes a voucher system would allow for greater consistency in service provision, which is key for individuals with autism. Ms. Demarest commented that a

¹A copy of the handout is on file in the Legislative Information Center, Room 230 of the State House, Indianapolis, Indiana. The telephone number of the Legislative Information Center is (317) 232-9856, and the mailing address is 200 West Washington Street, Suite 301, Indianapolis, Indiana 46204-2789.

²A copy of the handout is on file at the Legislative Information Center. (See footnote 1).

³A copy of the handout is on file in the Legislative Information Center. (See footnote 1).

voucher system would also enable parents to pay for training for care givers.

Walter Thomas, Director of FSSA's Medicaid Waiver Unit/Aging & In-Home Services, stated that the federal government does not like the voucher system. Mr. Thomas stated that the state makes annual visits to service providers and can decertify providers. He stated that any service provider complaints should be directed to Barbara Bates at (317) 232-5110.

Jan Stenftenagel, parent of a son with autism and Autism Society board member, testified about her family's experiences obtaining services for her son. She explained that she applied for the Autism Waiver in October of 1995 and he was placed on the waiver in February of 1998. Ms. Stenftenagel's primary concern was whether autism or the ability to pay drives the waiver process. She expressed confusion about why her son's trust income would be an issue when parental income is not, particularly when no income has been distributed to her son from the trust. She also described the poor treatment she received from the Dubois County Office of Family and Children. Ms. Stenftenagel also commented that the state insists on paying for one evaluation of her son per year, despite the ten independent evaluations that had already been conducted. However, she stated that the waiver is invaluable because it provides for services that one can't even purchase privately. She distributed a handout detailing her experiences with the Autism Waiver.⁴

Beth Werner, parent of a child with autism, told the Commission that she waited for 19 months to get on the ICF/MR waiver. Ms. Werner stated that she has experienced the same problems as other testifiers, inconsistent caregivers and lack of insurance coverage due to the autism diagnosis. She testified in favor of a voucher system, no waiting list, increased services and better training of care givers. Ms. Werner commented that because she works for the Division of Family and Children, Medicaid and the waiver process wasn't a problem because she knew the system. Rep. Summers echoed Ms. Werner's testimony, stating that service providers are not training the care givers they employ sufficiently.

Annette Kristoff, parent of a child with autism, testified that her child has been on the ICF/MR waiver for two years and that her experience with the waiver is positive, because it enabled the family to function more normally by keeping her autistic child at home. Ms. Kristoff stated that her child was on the waiting list for four years (one year more than is normal because a caseworker didn't realize it is possible to sign up for two waivers simultaneously). She testified that there aren't sufficient care givers in rural areas. She recruited a friend to provide services, asked the provider to hire her and insisted her salary was fair. Ms. Kristoff explained that she is now seeking physical and speech therapy services for her child. She closed her comments by asking the Commission to give families more power and resources.

Steve Kristoff, parent of a child with autism, testified that since families are doing most of the work in obtaining services for their children, the voucher system is the next logical step. Mr. Kristoff proposed a tax credit for people not on the waiver to help pay for services. He suggested that a credit would free resources for families who are on the waiting list. He proposed that the tax credit be applied only to those with high incomes who are on the waiting list, and that another benefit of a tax credit would be that some families may choose to keep the credit rather than go on the waiver, thereby making the waiting list shorter.

Angi Kerr, parent of a child with autism, testified that she didn't know about the waiver until recently. She stated that her insurance company would not cover physical and speech therapy for her son with autism, but that it would cover exactly the same services for her other son, because he's developmentally disabled, not autistic. Ms. Kerr also expressed frustration at the lack of respite care available. She stated that she has incurred \$10,000 of out-of-pocket expense for basic services for one year, and that in six months, her son progressed from a ten-

⁴A copy of the handout is on file in the Legislative Information Center. (See footnote 1).

month old's ability to a one-and-a-half year old's ability. Ms. Kerr testified that her son receives inconsistent diagnoses because when her son receives services he makes progress, but when he doesn't, he regresses considerably.

John McGrew, parent of a child with autism, clinical psychologist and professor at IUPUI, stated that the service delivery problem results in a "Catch-22" situation. He explained that research shows that treatment is most successful when provided to autistic children under six years old. However, he stated that most children are not diagnosed until the ages of two to four years of age. He observed that by the time they are on the waiting list for three years, they are over the age of six and the window of opportunity for the most success is lost. Mr. McGrew stated that state dollars are best used to get rid of the waiting list so that children could receive services earlier, when they would be most effective. He argued that this approach would increase the chances that they can become better functioning and less costly to the state.

Barbara Pierce-Cruise, parent of a child with autism and a clinical social worker at Purdue University, testified that the insurance plan she has through Purdue will not cover services for her child due to the autism diagnosis. Ms. Pierce-Cruise stated that Purdue handles it by offering a flexible spending plan with a tax break.

Donna Forthofer, parent of a daughter with autism, testified that her daughter is on the waiver but she still incurs enormous medical bills because she sees a doctor in California who specializes in autism, and Medicaid will not pay for services received outside of Indiana.

Kathy Pratt, Director of the Indiana Resource Center for Autism, testified that the incidence of autism is rising in Indiana. Ms. Pratt estimates that approximately 27,000 in Indiana are autistic, making autism more prevalent than other disabilities that receive greater visibility. She distributed a handout concerning autism in Indiana.⁵ Ms. Pratt testified that the Indiana Resource Center will train providers and care givers without charge, and indicated that a provider's only costs would be transportation and salary. She explained that since training is not billable to Medicaid it is part of a provider's administrative overhead.

In response to the public testimony, Rep. Summers shared her priorities for the remainder of the interim session with the audience. She stated the her goals are to concentrate on the following issues: the length of the waiting list, the lack of insurance coverage for individuals with autism, the complicated process of applying for the waiver, and the lack of training for care givers.

John Dickerson, representing the ARC of Indiana, thanked the Commission for their work and encouraged parents and other interested parties to step up lobbying efforts through their associations and to their individual legislators.

Rep. Summers then thanked Mr. Thomas for his consistent and patient assistance to the Commission.

ADJOURNMENT

Rep. Summers set the next meeting for September 8, 1998 at 10:30 a.m. With there being no further business before the Commission, Rep. Summers adjourned the meeting at 12:30 p.m.

⁵A copy of the handout is on file in the Legislative Information Center. (See footnote 1).